

Stollery Family Centred Care Network

Annual Report: September 2012 to August 2013



It is the over 1,600 hours on 562 different occasions that families have volunteered in this past year, along with the commitment of staff, physicians, and senior leadership that collectively champion the Stollery in moving beyond a philosophy of family centered care, to a set of values that are 'operationalized' in action.

The strength of the FCC Network is derived from the multiple perspectives of key stakeholders through a collective membership of over 470 families, staff, physicians, senior leadership, and community representatives.

The Network is instrumental in moving the Stollery towards the **FCC vision of being a leader in Family Centered Care** by:

- **Placing children and youth at the centre of how we provide care.**
- **Recognizing the family as valued members of their child's care team and in the operations of the hospital.**
- **Aspiring to practice family centred care in a: collaborative, consistent, and continuous way.**

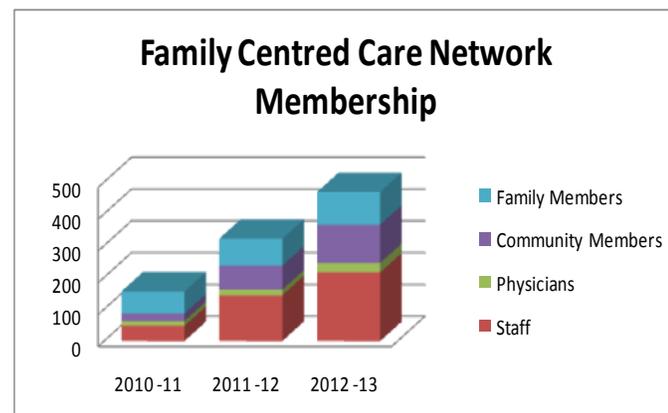
There are currently two formal groups that set the direction and guide the overall work of the FCC Network. The **Family Centred Care (FCC) Council** is a formal group of 25 members: 11 parents, 3 senior management, 4 staff, 4 physicians, 2 previous patients, and 1 sibling. The Council sets family centered care priorities for the Stollery and Network activities. The **NICU Family Advisory Care Team (FACT)** is a committed group of 26 families, staff and physicians, collaborating to improve the Neonatal Intensive Care Unit experience at the two Stollery NICU sites.

The key to successful growth over the past 4 years is that the FCC Network provides

opportunity for:

- Family members to be involved in a wide range of initiatives in collaboration with staff
- Members participate in family centered care in ways that best suit their skills and interests
- Activities range from reviewing and editing policy or family educational materials by email to presenting to health professionals at Grand Rounds in our Family Talks program
- Membership is flexible and supports the involvement of people from remote and rural areas.

Those who are just curious and want to know what is going on receive a monthly electronic Primer, and are just as welcome as those who want to be fully engaged in operational activities such as committee meetings.



The Influence of Stories:



Learning from stories is something we appreciate from childhood and into our professional lives. **We are fortunate at the Stollery to have families inspire us through their stories on over 84 occasions in this past year.** New staff orientations, resident and fellow training, nursing student classes, conferences and grand rounds are some of the venues families have contributed to care by:

Reminding us of what motivated our choice of profession:

"Thanks for sharing, it's encouraging to hear your stories and inspirational. Families are why I love my job!" - PICU Nurse

Encouraging us in how we provide care:

"This was a GREAT presentation! I loved hearing about your experiences I hope to impact peoples' lives the way other nurses have impacted yours. Your messages were so great. Thank you for sharing your stories!!" - New staff Nurse



Helping us translate theory into lived knowledge:

"Very candid, very interesting to see the family's point of view instead of always medical or family perspective based on theory" - MacEwan University Nursing Student

Influencing our professional practice:

"People like yourselves are to be commended for taking the time and making the effort to ensure we realize our actions make a difference and through this improve the care for all our families who visit us."

Clinical Nurse Educator



Families appreciate the opportunity to share their unique perspective.

"I have a passion for the training of fellows and the future care of infants. If by sharing my experiences I can help staff prevent negative interactions with other families it is all worth it."

Family Presenter

"Your stories really impacted how we care for our patients and families. I am much more aware of what the family is feeling and try to take an extra moment to communicate what is happening with them to help ease their anxiety"

- Neonatal Fellow

Family Centered Design:

When designing a hospital space there are many perspectives to consider for safety, comfort, and efficiencies in care. One of the important voices is that of the family that brings important insights to the planning and designs on two current projects: 1) an expanded Operative Services and Day Surgery area, 2) and a new Ambulatory Clinic.

The consistent presence of families on Design Committees and in discussions with architects and interior designers ensures considerations, like the following, are included in the planning:

- The sooner the child knows it is a child's space the better experience it is for everyone.
- Long wait times and time transporting between areas decreases children's ability to tolerate tests, increasing child and parent anxiety and stress, exam times, and need for repeated appointments and tests.
- It is necessary to have room for wheelchairs and strollers – recognizing that some children come with extra medical equipment as well. Families can't easily leave the strollers in the hallway, as they need to bring the attached medical equipment with the child.
- Lower the desk, so receptionists can also see and greet the children as well as the families.
- Use one of the alcove waiting areas as a quieter space for children with sensory sensitivities – with snoozalone, quiet music, etc.
- Use of pagers is especially important for children with Cystic Fibrosis who cannot be

in the same area as other children with CF.

- Possible ideas to engage preteens and teens are accommodating electronic gadgets, light constellations and pictures.
- Include designs that children can follow along the hallways to help them find their way (as well as the parents). It keeps them interested in coming to the appointment.
- It is so important to be able to easily find your way to and from treatment areas – so it doesn't feel like a maze.
- Designs, not just colors, in the rooms and above exam tables provide something for the child to focus on during uncomfortable procedures.

Families are instrumental in transforming spaces.

Until spring of 2013, a new family's first impressions of the NICU at the Royal Alex site were created when entering the unit via a white hallway from the Lois Hole Hospital for Women. The NICU Family Advisory Care Team enthusiastically took on this project and contacted the Victoria School for the Arts and transformed the space, through paint color and twenty-six pieces of students' art. This important collaborative project provides an important place for families to have a visual break and to recognize hope through the creative work of young people, when entering an often unexpected and difficult time in their child's early life journey.



BEFORE

NICU Entrance Renovation at the Royal Alex

AFTER



Strengthening Partnerships with Families in the Care of their Children

Families often describe their experience of arriving at the hospital with their child requiring urgent care to be like “landing on another planet”. All of their usual roles, routines and tasks in taking care of their family members have been altered; they are learning a new language, adjusting to a whole new climate, in an extreme situation!

Members of the FCC Network are reaching out to inpatient families to support them in this very difficult transition through a number of [Peer Support initiatives](#).

Coffee Comfort and Conversation is an opportunity for families in the PICU and NICU (David Schiff site) to meet each other and mutually support each other during this very challenging stay in an intensive care environment. This weekly program is co-facilitated by the Spiritual Care Chaplain, a trained Supporting Parent, and the Social Workers of NICU& PICU.

Family Bedside Orientation Pilot Project – 5G4 is a medical unit that has taken initial steps in engaging FCC Network families in providing orientation at the bedside to inpatients and their families. The supporting parents provide information on hospital facilities and services, clarify families understanding of the roles of staff, and encourage families to engage in the care of their child as partners in their child’s healthcare team to the degree in which they feel

comfortable.

Acknowledging ‘Baby’s Firsts’ in the NICU - Celebrating the growth and changes of a newborn infant is something every parent wants to do. However, when you are with your newborn in the NICU your baby’s “firsts” are much different than highlighted in a purchased baby

book. The NICU FACT is creating stickers and a calendar to support families (and staff) in

celebrating the unique “firsts” of babies in an intensive care.

NICU Parent Group (RAH site) – Graduate families are invited to speak with inpatient families at a parent group hosted by NICU Social Work staff. The goals of the group are to: create a safe supportive and informative atmosphere for parents; share learnings, insights and knowledge about the NICU; to lessen stress and worries of parents; and to provide families with tools to successfully manage their family’s time in the NICU.

PICU Transfer Study - The FCC Network has been fundamental in the implementation of a project called the “Pediatric Cardiac ICU Transfer Study” with Dr. Ian Adatia, a pediatric cardiac intensivist at the Stollery and a member of the FCC Council, and Elina Williams Pediatric Cardiac Research Nurse and Study Coordinator. The grant proposal was selected for funding by the Canadian Medical Protective Association. The “PICU Transfer Study” aims to investigate the effect of direct parental involvement in transfer rounds and to alleviate parental anxieties and improve patient safety when preparing to move from ICU to the wards.

Members of the FCC Network authored a handout to educate parents about the goals of meeting with their medical team, empowering parents to engage in transfer rounds in a way meaningful for the family and their child. A specially trained team of “Supporting Parents” offer one-on-one peer support to families who feel they could benefit from discussion with those who have gone before them. This is an externally funded randomized controlled clinical trial with Family Centered Care at the core, aiming to provide solid research data to support the work of improving the experience of families during their child’s hospitalization.



Engaging Families in the Operations of the Stollery

A critical way in which care is influenced is by engaging families in the operational functions of the Stollery – being on hospital committees, influencing protocols, policies and procedures, having input on educational materials, and in the hiring process of new senior level staff.

Families are members of the following hospital **committees / working groups**: Stollery Council, Expanded Management, Pain Management, NICU Regional Operations, Breast Milk Working Group, 23 Week Gestation Resuscitation Group, NICU NIDCAP Audit, World Prematurity Day, NICU Palliative Care focus group, FCC Standards of Practice working group, School Program and Transitions Initiative.

Families have had input on many **educational materials** developed for families, with significant input on the following: Falls Prevention, Trach - Vent Discharge Binder, Controlling Your Child's Pain After Surgery, Dayward Visual Story, NICU Research Pamphlet, NICU Volunteer Cuddler form, content for an NICU Prenatal Orientation video, Electronic Devices Used on the NICU.



Families have reviewed **protocols, policies and procedures** including: Goals of Care, Direct Admission, Patient Information Telephone Inquiries, Prevention of Pressure Related Injury, Stollery Visitor Policy, and pain management protocols.

Families have participated in **senior level interview panels** for the Executive Director of the Stollery, Patient Care Managers for the following units: Oncology, Child Health Networks, Pediatric Intensive Care, Neonatal Intensive Care; Neonatologist Interviews, and the NICU Regional Director Search and Selection.

Does it Make a Difference?



Families in particular gave high ratings and wrote many positive comments regarding the respectful, supportive care they received, and the degree to which they felt they were partners in care.

The 2013 provider responses were significantly higher than they were in 2010.

FCC Survey 2013

The Stollery Children's Hospital has taken significant steps to integrate Family Centred Care (FCC) into its operations. It is now looking to develop a formal set of Standards of Practice to more solidly institutionalize FCC into all areas of its patient care.

A literature review was conducted that highlights a number of existing best practices in Patient and Family Centred Care (PFCC) in order to provide the Stollery with resources it can draw from to aid it in the development its own Standards of Practice. Some of the key findings indicate that organizations that have committed to incorporating practices that fully engage families in the care of their children and in the operations of the hospital (including family centred bedside rounding and shift reports, discharge practices, family access to electronic medical records, incorporating family centred principles in human resources hiring and evaluation processes, engaging families as advisors in hospital committees and policy decisions) experience the following results:

- Increased patient and family satisfaction
- Decreased lengths of stay
- Reduced medical errors
- Decreased nursing vacancy rates
- Increased staff morale

A Stollery specific Family Centred Care Survey was distributed to staff, physicians and families during the months of May and June 2013. The *Measures of Processes in Care* tool (CanChild Centre for Children with Disabilities, McMaster University) assess family-centered behaviors of Health Care Providers. It was created to examine the way in which care is delivered (the process of care) and the impact that this service delivery has on children and their families. It specifically measures how families perceive the interpersonal and informational aspects of the

care they receive. It also allows healthcare providers to identify those aspects of care that could be improved. The Evaluation Report was completed by AHS Evaluation Services, Data Integration, Measurement and Reporting, in conjunction with members of the FCC Council. Primary analysis of qualitative results was undertaken by Dr. David Nicholas of Nicholas & Associates.

Results indicate: Both quantitative and qualitative data provide a strong endorsement for FCC and its delivery at the SCH. Families in particular gave high ratings and wrote many positive comments regarding the respectful, supportive care they received, and the degree to which they felt they were partners in care. Surveys received from day ward contained higher ratings in all areas of measurement as compared to surveys received from inpatient units and outpatient clinics. Provider ratings were also quite high, although they were slightly lower than those given by families. Both groups identified the provision of information, both general and specific, as areas to be improved upon. The survey had previously been conducted with healthcare providers in November 2010. The 2013 provider responses were significantly higher than they were in 2010.

Recommendations:

- Provide more and better resources for specific conditions and community supports.
- Streamline and clarify referral and booking practices.
- Ensure information is consistent across providers.
- Consistently involve families in rounds.
- Evaluate and make changes to the physical space to ensure the whole family is accommodated

This valuable information will guide the Stollery in their journey of excellence in providing patient and family centered care.

Communicating and Sharing our Work with Others:

Inpatient families and those who are receiving ongoing care can now receive the **Stollery Daily News**, an email that highlights activities children and their families can participate in at the Stollery on that specific day. Tips and information are also shared to help make their stay more comfortable. This initiative was started January 2013 and currently 200 families receive the email daily.



A **Family Centred Care Primer** is an electronic newsletter that is distributed to the members of the 450 Family Centred Care Network members (staff, families, physicians, management, community organization) and inpatient families, with a total monthly distribution of 650 people. It highlights the key initiatives that the Network has been engaged with during that month and invites network members to be involved.

Sharing our work with others beyond the Stollery is key to furthering family centred care generally in healthcare, and in our own growth and learning. Members of our FCC Council and NICU Family Advisory Care Network have been attending and **presenting at the annual Canadian Association of Pediatric Health Centres Conference and affiliated Canadian Family Advisory Care Network meetings.**



At the 2012 Conference Stollery FCC Council members presented on: Orientating and Training Family Advisors, Moving PFCC Forward –Senior Leadership Perspectives and hosted poster presentations on: Peer Support, and Improving Communication and Strengthening Relationships by Implementing New Whiteboards by Every Bedside.



Coverage in professional magazines (CARNA, NIDCAP Observer), AHS publications, and the Stollery Children's Hospital Foundation Hero Magazine and Global News Spots also help us share our news with a much broader audience.

Your Support Makes the Difference:



As highlighted by the results of the survey, there are many staff and family championing the continued growth of family centred care practices at the Stollery.

The FCC Council is now formally recognizing individuals, groups or organizations who have been or are currently instrumental in unleashing the climate of Family Centred Care at the Stollery Children's Hospital. Staff or family are nominated and recipients are recognized as **"Family Centred Care Champions"**. Champions are presented with a specially designed FCC Champion pin at an event / meeting where they can celebrate with their peers or other members of their team. They are also recognized in the monthly FCC Primer.

The tremendous commitment of many family representatives, staff and physicians on the FCC Council and NICU Family Advisory Care Team and the continued support from Senior Leadership: Linda McConnan (now retired)

and Tracy MacDonald, Executive Director; Christine Westerlund, Director Critical Care and Operative Services, Monica Whitehead, Director Inpatient and Ambulatory Care, and Dr. Christine Kryiakides, Stollery Medical Director have been instrumental in our ongoing journey of being leaders in family centred care.

A special thanks to the Stollery Children's Hospital Foundation for their ongoing partnership and financial support of the Family Centred Care Initiatives.

Thank you to AHS for their ongoing commitment to patient and family engagement throughout our provincial healthcare system. Collectively these efforts are making a difference to the care of the patients and families in our communities.



Family Centred Care Council Members 2012-13

Current Members:

Family Members:

Karen Calhoun
Simone Chalifoux
Shannon Robertson
Dee-Ann Schwanke (co-chair)
Donald Lepp
Allan MacDairmid
Jodie Craven (co-chair)
Ali Martens
Amanda Proctor
Poonam Madan
Carol Carifelle-Brzezicki

Previous Patients:

James Coughlan
Andrew Hendricks

Physicians:

Dr. Ian Adatia
Dr. Heather Dreise

Staff:

Gayle Parks Krupa
Lynett Kane

Management:

Christine Westerlund
Monica Whitehead
Tracy MacDonald
Tim Tsounis
Sarah Kane Poitras

Members Completed

Service on Council:

Family Members:

Loreen Gomes
Darlene Thompson

Karen Klak

Physicians:

Hannah Weistangel

Staff:

Dianne Tuterra

Lois Hawkins

Management:

Linda McConnan

NICU Family Advisory Care Team Members 2012-13

Current Members:

Family Members:

Charlene Cardinal
Jodie Craven
Roberta Davis
Kim George
Kevin George
Maria Hambly
Nicole Lyste,
Allan MacDairmid (co-chair)
Amanda Proctor
John and Brenda Tachynski
Joyce Tang
Kristy Wolfe

Physicians:

Dr. Sandra Escoredo
Dr. Elsa Fiedrich
Dr. Juzer Tyebkhan
Dr. Michael VanManen

Staff:

Denise Clarke (co-chair)
Donna Gibbons
Michelle Gurin
Karen Long
Valerie Levesque
Donna Organ
Amanda Schroeder
Management:
Christine Westerlund
Monica Whitehead
Doryta Foote*
Daisey Garvey*
Cathy Hill*
Shelley Jakubec*
Lisa Leniuk*
Carol-Anne Middleton*
Karen Pelletier*
(*shared position)

Members Completed

Service on FACT:

Family Members:

Roxie Malone-Richards

Physicians:

Dr. Paul Byrne

Staff:

Andrea Brand
Kathleen Brown
Michelle Gurin
Joanne Mitchell

Would you like to join us?

We welcome you to join our Family Centred Care Network! Please contact us:

Call the Stollery Family Room: 780-407-7255

Email us at: StolleryFCC@albertahealthservices.ca

Check us out on the Stollery Website:

<http://www.albertahealthservices.ca/5520.asp>



Submitted by FCC Council Co-Chairs, Dee-Ann Schwanke and Jodie Craven; Manager of FCC, Heather McCrady, and FCC Coordinator, Marcel Panas.

Summary of Family Interactions and Volunteer Hours

STRATEGIC PRIORITY	# of Family Interactions			Family Volun- teer Hours
	2010-11	2011-12	2012-13	2012-13
Enhance Communications	8	10	30	58.5
Create Sustainable FCC Infrastructure	92	83	231	690
Enhance Family Centred Care Design	20	27	35	78.5
Engage Families in Operations Committees or Groups	22	37	35	82
Interview Panels	6	8	9	44
Education Materials	38	25	48	66
Policies and Procedures	9	18	32	42
Improving Services	16	47		
Documents	9	6		
Strengthen Partnerships with Families in Healthcare of Child				
Peer Support	14	57	25	51
Whiteboard Transformation Project	3	15		
Engagement of Staff & Physicians Family Talks	45	72	84	435
Enhance Stollery Specific FCC Quality & Research	13	20	33	63
TOTAL	295	425	562	1610